

COMMUNICATING TOGETHER

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AS ABILITIES CHANGE

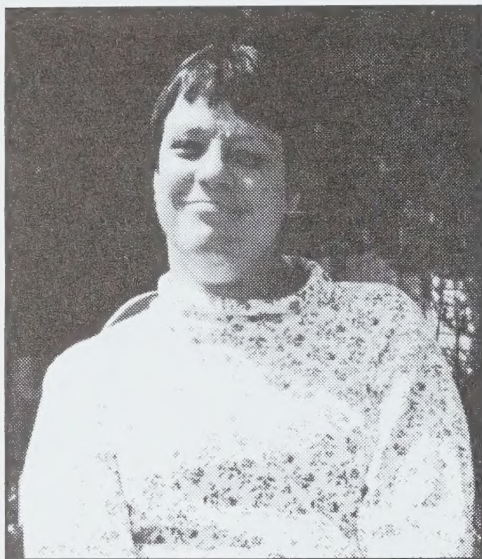
COMMUNICATING TOGETHER VOL. 16, NO.3/FALL 1999



Theme for this Issue: Caregiving

Caregiving

NOLA MILLIN



Nola Millin

*Those of you who know Shirley McNaughton will understand that whenever she needs you to do something, she gives you this distinct look that is impossible to say "no" to. When we held our editors' meeting back in April, I got one of those looks when Shirley and Peter both realized that neither one of them would be in the country to take charge of our fall issue of **Communicating Together**. So, the bottom line is, here I am back in the "editor's seat". In all honesty, I feel honoured that Shirley and Peter have looked to me to be their fill-in, but then again, how can you say "No" to Shirley?*

When I realized the theme of this issue was *caregivers*, I thought it was appropriate that I take on the editor's responsibilities. It only makes sense to have a person who relies on caregivers to take charge of an issue on caregiving. If you are picking up **Communicating Together** for the first time, you need to understand that because I have cerebral palsy, I have to rely on caregivers every day of my life. I can do more for myself in my own apartment but I need caregivers to dress me and prepare my meals. When I go out, I'm more dependent on caregivers to feed me and help with other physical needs.

Being a caregiver is a difficult job, I'm sure. First of all, the general public doesn't understand the role of an attendant, or caregiver. The apartment building where I live has round-the-clock attendant care staff on site at all times. The staff does not have any jurisdiction over the tenants. They are just here to help us with whatever we physically can't do for ourselves. Unfortunately, the public thinks that the attendants are here to supervise us. On a number of occasions, different neighbours have brought a certain nonverbal tenant back to the building thinking that he has "escaped." In reality, the man does not appreciate the push back to the building when he is heading somewhere in the opposite direction. Also, when I'm out, strangers tend to direct questions to my attendant rather than to me.

The second difficulty that a caregiver faces, especially working in a building like this apartment complex, is the expectation of each person to whom they are giving services. I know that there are two extremely different opinions from the tenants just within this building. Some tenants feel the attendants should remember every aspect of their care especially if they have the same routine each day. Because there are twenty-three tenants in the building each needing special care, I'm opposed to this view.

I don't feel an attendant should be expected to remember the details of our care, especially such important details as which medication we get. The tenants should be responsible for their own medication and the staff should follow our instructions, and give us the medication whenever we ask for it. I firmly believe that tenants should direct their own care. They should give an attendant direction on what they need done or which medications need to be taken. I have a note on my fridge that says, "Unless you have developed an ability to read minds, please ask me what I want. Regardless of whether or not you do my care everyday, do not assume you know." I had to put that note up because I had attendants coming in and making things for me without waiting for my direction. They'd say, "Well, you usually have —." I pointed out the key word in the sentence was "usually" and "usually" doesn't mean "always!" Some attendants like my

sign while others have made negative comments about it. I think those who have made the negative comments are the attendants who want to get the job done, instead of taking time to make sure they are doing what I need them to do.

As you read this issue, it is obvious that, depending on the recipient's needs, the role of a caregiver can be quite diverse. Caregiving is a very personal job. Since each person is different, the care provider has to be sensitive to the various requirements of each individual.

Josh Wyse, whom I identify with in many ways, wrote the feature article for this issue. Like me, Josh lives in a supportive living facility. He has many caregivers coming in and out of his life. He shares with us some of his frustrations of having to rely on attendants and how the quality of care varies from attendant to attendant. I can definitely understand what Josh is saying because I share the same frustrations in the residence where I live. As at Josh's residence, the staff turnover at my apartment building is phenomenal. Staff turnover is difficult to handle because it means getting used to new people and doing the training all over again. Josh points out that many caregivers tend to "mother" us. This shows how difficult the role of caregiving is. Around this building, there are tenants who want the attendants to "mother" them and there are other tenants, such as myself, who don't appreciate it. I'm glad that Josh shared some of his insights with us. It only shows that being a recipient of personal caregivers can be as difficult as being a caregiver.

In the *As Communication Changes* section, Audrey McGee and Steven Hanlon talk about what they feel makes a good caregiver. It is not surprising that in each of their articles, Audrey and Steve mention that it is the *time* that caregivers spend with them that is so crucial and the most appreciated. Steve shares how he likes the nurses who joke and tease. Interestingly, Steve considers Audrey one of his caregivers and Audrey remarks how she plays dominoes with him because she knows Steve enjoys playing. This illustrates the fact that it isn't always the physical things that people do for us that make people good caregivers. Just as important if not more so is the emotional and social support that people give each other.

I'm pleased to have a *Perspectives* article and poem by Kari Harrington. Kari is a former associate editor of **Communicating Together** who now writes occasionally for us. In her article, Kari talks about two of her favourite caregivers. She reveals how some caregivers go the "extra mile" by doing things for her that go beyond their job. Also, Kari talks about how the positive attitude of an attendant can be very helpful. These caregivers have become quite special to Kari. Again, I can identify with Kari because there are a few people who are more than just attendants to me. They are friends. One attendant, in particular, treats me like a sister and we "fight" as well as any two siblings do.

I'm glad that Tracy Shepherd provides us with an article from a caregiver in *Clinically Speaking*. We hear the perspective of an

educational assistant, Doris MacIntire, who provides care to a student. This issue of **Communicating Together** is definitely a little unbalanced as many articles deal with the recipient's view of a caregiver. Doris' article offers some insight into what it's like to *provide* care and support to someone. Doris expresses the delight she sees when a child can have independence with their AAC device, when it works! The fact that it sometimes seems to break down for no reason at all is a glitch that haunts most, if not all, AAC users!

My *Reflections* Section has the perspective of a mother who has caregivers for her daughter. In the section, I provided my own evaluation of what I look for in a caregiver. I talked about two special friends in my life who provide care for me when the occasions arise. On thinking about it, I realized that many of my close friends provide care for me. If a friend takes me out he or she knows that I will need to be fed or might need assistance in the washroom (note: I only allow females to provide this assistance!). I shared some of the experiences that these two friends and I have had together. One of the two friends I've chosen to talk about is very familiar to **Communicating Together** readers — Tracy Shepherd. The other friend is Colleen McGaffey. Colleen is a former associate editor of **Communicating Together**. In fact, I met Colleen when I became an associate editor. Let's just say it's a good thing both Colleen and Tracy have a great sense of humour or they wouldn't take me places any more!

George Pigache, another new associate editor, identifies some very interesting implications related to the move towards commercial, profit-making companies providing care for AAC users. He questions the extent to which the insertion of the profit motive into the caregiving equation compromises the quality of the care.

Peter Lindsay continues to teach people about the internet in *Using Technology*. I wish he would have written these columns about five years ago when I was just beginning to become familiar with e-mail, the internet, and chat rooms. In this section, Peter talks about the pros and cons of chatting. As a fully literate AAC user, I use chat rooms but, as Peter points out, I'm leery about some of the people I chat with. One of the functions I use chat rooms and instant messages for is to "talk" to

friends I know. Often, I call a friend and he knows my voice and he will know that I need him to get online so I can tell him something.

Shirley McNaughton is just back from some interesting meetings in South Africa. She was excited to see that Paul Marshall had an article for her *SymbolTalk* section. Paul discusses how he learned to read and the impact that face-to-face communication had on his learning process. It is a provocative article that Shirley promises to follow up in the next issue.

Finally, we have a letter from a committed reader, Peg Johnson, describing an interesting program in which she is involved.

As an aside, I would like to take the opportunity to thank Paul Marshall and acknowledge all of the work he has done on this

issue. He has had the responsibility of doing the desktop publishing for the first time as well as keeping me on track. He has been a caregiver to me as I've experienced health difficulties and haven't been able to meet deadlines. Paul has had to "yell" at me via e-mail on more than one occasion to take it easy and has worked around my unexpected delays without complaint. So, thanks Paul, for your poem and for putting what you preach into practice.

As you read through this issue I know you will see that the role of a caregiver is a unique one. It takes a certain person to provide physical and/or emotional assistance to another individual. To me, the best relationship with a caregiver is the one where both parties care about each other. What kind of caregiver are you?

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Associate Editors April 1999



Back Row: Peter Lindsay Paul Marshal Suzanne Clancy Bob McNaughton Geb Verburg George Pigache

Front Row: James Stuart Shirley McNaughton Nola Millin Tracy Shepherd

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Caregiving and Independent Living

JOSH WYSE

Josh is a twenty-five-year-old man living with Duchenne muscular dystrophy. He lives in a middle sized city in his own apartment and enjoys working on his computer, free lance writing and watching sports. He has been receiving care for most of his life. At the present time he lives in his own apartment with attendant care services provided on a twenty-four-hour basis. According to Josh, "Living with a disability is easy. Depending on other people is the hardest thing to get used to."

Caregiving is an essential part of a disabled person's life. Given the choice, would you want people coming in and out of your life all day long? The biggest sacrifice to living independently is one's privacy. We appreciate the help, but at the same time we resent the intrusion.

It is very frustrating directing someone step by step how to assist in the activities of daily living when you would rather do it yourself. In my experience, the quality of care from one attendant to another varies greatly. For example, how can a group of attendants learn the daily routine of twenty five different consumers and expect to remember it for the next time? The turnover in staff in most supportive living facilities is far too high to maintain any consistency of care.

From my perspective, the independent living philosophy is that caregivers are to assist me on a physical level as my arms and legs. Unfortunately however, people lose sight of the fact that we ourselves are adults with a voice (be it sometimes augmentative) and a brain. The nature of this business is that most caregivers tend to be women, who naturally feel the need to 'mother' somebody. I find myself saying on many occasions: "I have a mother. I don't need another one". For the most part women naturally make good caregivers, but ultimately the consumer has the right to live his or her own life the way they see fit. With that in mind, there is a great need for more men to take the role of the caregiver. Keeping with society's thinking, the disabled population welcomes men as an asset to the health care field.

"Living with a disability is easy. It's depending on other people that is the hardest thing to get used to."

A good caregiver is measured by their attitudes towards the disabled consumer and their approach to providing the care. For example, caregivers should consider what it would be like to be on the receiving end of the care. In talking to caregivers over the years, I have come to the conclusion that most able-bodied people take their own abilities in life for granted. Try for just one day to direct someone else to do a simple task like brushing your teeth the way you like it done. I would expect that one would find this very difficult, not to mention

tedious. People make the mistake in life of thinking of themselves as invincible, when in reality anybody can become disabled at any time and at any age. I didn't choose to have a debilitating disease and to live my life in a wheelchair. Christopher Reeves did not choose to fall off that horse and suffer a spinal cord injury. Similarly, even with the recent advances in medicine and the increased life expectancy of the average person, we should remember that as we get older, we get more prone to falls and diseases that are debilitating, that will require care of some kind.

With that in mind, caregivers set restrictions on the lives of the people they take care of. For example, just as the average person from time to time may decide to sleep in some morning, a consumer may too decide that they would much rather sleep in than get up on a particular morning. The difference is that the consumer may run into a caregiver who expects the consumer to follow the schedule to the caregiver's liking. Why do the lives of the disabled have to be reduced to a certain time frame and to scheduled bookings with no exceptions to the rule?

Perhaps when we talk about caregivers, we sometimes forget that to them, it is just a job, not someone's life. Unfortunately, the money has more to do with who becomes a caregiver than any special skills in caring. This is not to say that all caregivers lack the necessary compassion for this type of work. It is to say that some people seem to approach any job with a lackadaisical attitude.

So it would appear that for quality of life and care for persons with a disability to be achieved, the role of the caregiver and the philosophy of independent living must be redefined. The future goal for long term health care should focus on increasing the hours for in-home care. The population of persons with disabilities should be budgeted enough funds per year to hire their own caregivers. This would allow the consumers to discuss their personal care needs with each potential care provider. In supportive living arrangements, the wide range of disabilities that affect the consumers can be easily generalized. For example, when caregivers are not given sufficient knowledge about the various disabilities, they tend to put everyone in the same category. The care levels and needs of a person living with muscular dystrophy is often confused with the needs of some one with multiple sclerosis or spinal cord injury. Some disabilities require special care due to the consumer's respiratory condition. An example would be those who are ventilator dependent. They obviously require caregivers with more specialized training. Having one approach to care, together with appropriate training and qualifications and a genuine respect towards the client will promote consistency of care and ultimately make the life of the consumer easier.

Due to the lack of in-home care, the person with a disability has limited choices as to where he or she can live and work. The cost for running group homes, supportive living facilities and even nursing homes is much higher than it would be for in-home care where consumers could live a normal life with care provided. Likewise, consumers with a disability are usually unemployed due to unavailability of caregivers in the work-place.

Changing society's thinking with regard to the people with disabilities and the need for quality caregivers will hopefully create a better awareness and understanding about disabilities in general. Individuals who are disabled are still sometimes considered second class citizens with respect to their right to live normal lives, as contributing members in the community.

Although we have overcome many prejudices, the consumers still fight for their right to have a normal life that includes relationships and family. Everyone, including those who have a disability, need to love and be loved. The assumption is that people with disabilities do not need companionship and especially not with an able bodied person. In most cases the social network of the person with a disability is made up of their nurses, their attendants and their therapists who are responsible for their care needs. On some level, the relationship between a caregiver and a consumer is a very special one due to the intimacy and closeness of their personal contact. In all likelihood this friendship could become more serious and feelings of affection and love may be experienced. In my personal experience for example, my able bodied girlfriend is often asked if her relationship with me is purely platonic. These questions even come from those people who are very close to me and should know better, such as my mother, or my sister or a sympathetic friend. Likewise, most people find it difficult to understand our relationship as a couple. They will say that she is an angel and is just taking pity on me. It is because of my disability and my special needs that people will not understand a one-time caregiver becoming involved in such a relationship where they believe I have nothing

to offer her. Who better to spend their life with a disabled person than someone whose life's work is devoted to caring for people who are unable to care for themselves.

It is my hope that all disabled people look at life as I do, take nothing in life for granted and live every day to the fullest. My personal insight on the whole idea of 'the caregiver' may sound somewhat negative, but it is actually the best way I know to create awareness and hopefully promote change in our health care system. For too long now, society has stereotyped the population of persons with disabilities. Although we have gradually seen some progress towards discouraging this narrow minded thinking, we still have a long way to go.

On a positive note, I have known some very good caregivers who respect my privacy and my right to be independent. With any luck I may be fortunate enough to see a cure for muscular dystrophy in my lifetime. If I do, that will in large part be due to the work of Jerry Lewis, the ambassador and national caregiver to all the people suffering from many neuromuscular diseases. Likewise, Christopher Reeves is fighting to change society's thinking and to spread a message of hope to all who suffer from spinal cord injuries so that they too may walk again. Chris also is a national caregiver. Who better to create world wide awareness about the lives of persons with a disability than someone who has experienced life from outside his wheelchair. It is this kind of determination, patience and compassion that we can only hope future caregivers will bring to this field.

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AS COMMUNICATION CHANGES

Our Experiences with Caregiving

ALDA STEPRANS



Alda Steprans

*Those of you who read **Communicating Together** regularly know that Audrey McGee is a regular contributor. She suffered a stroke some years ago. Because she is slow to learn she did not do well in a rehabilitation setting, but continues to enjoy learning at the chronic care hospital she lives in. Audrey uses a wheelchair and relies on caregivers for all her needs. Although Audrey cannot speak, she can spell to make her needs known.*

AUDREY MCGEE

The best caregivers take time to do everything for me. They don't just wash me and get me up in the wheelchair. They comb my hair, put on my perfume and do extra little things to make me feel pretty, like put some make-up on for me and fix little things around my room. They spend that little extra time on me.

There are lots of different kinds of caregivers in the hospital, from nurses to kitchen and cleaning staff. The maintenance staff give me special things for my chair that help me be more independent. The kitchen staff will give me drinks whenever I'm thirsty.

Even though I'm quite severely physically handicapped, and cannot communicate very easily, I can still care for others around me, too. I especially watch out for Steven, who has Huntington's Disease and also writes for **Communicating Together**. I'll often play dominoes with him, just because I know he loves playing games. It makes him happy.

I also let the staff know about other residents who may need help. One resident was out in the garden, unattended. I knew it was not safe for that person and was able to get help.

My grandson Shawn, his wife Karen and my great-grandson Cody also care about me a lot. They visit me often and take me on outings. I especially enjoy watching Cody growing and changing. My cousin, Louise, also comes to visit me. I love it when she takes me to the park. It's nice to get away, in good company.

One caregiver I really miss is our speech therapist (Nicole), who has left the hospital. I really appreciated her programmes. I'm very lucky because I have been attending the Aphasia Centre and still get speech therapy there. Lots of other residents here would benefit from having regular practice. I understand that there is a shortage of

speech therapists in the city. Those kinds of caregivers are very special and make a huge difference in people's lives.

STEVEN HANLON

The best caregivers in the world are the ones who bring me beer – ha, ha!

The volunteers are great. On Tuesdays they come in to play euchre. I love cards and other games, too. The nurses in the hospital where I live are good caregivers. They know what I want. The nurses wash, clean and feed me. As I said above, the good ones also bring me beer! I like to joke around and tease them and I like the ones who tease me. Humour is an important quality for a good caregiver. Many of the caregivers understand what I say, especially when I talk about beer.

My wife Kim is a great caregiver! She comes to the hospital to see me often. She brings me flowers. I like flowers a lot!

I miss Nicole, the speech therapist I had. She took lots of time to help me communicate better.

Audrey, the other resident who writes for **Communicating Together**, also takes good care of me. She's like my Mom. She makes sure I dress warmly enough when I'm out in the garden and she takes time to play dominoes with me.

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You Are the One

KARI HARRINGTON



Kari Harrington

The request to make some comments on my experiences with caregivers made me do a lot of thinking about the many different people who have had an effect on my life over the years. The caregivers I have had have been both good and bad. I decided however to talk about two good ones.

It is almost 10 years since I moved into Participation House where I currently live. During the first years here, I sometimes felt very, very down. I often cried when there was no one around to see me.

Then, along came Sharon Smith! She is a member of the Attendant Care Staff at my residence. All the aides are nice and caring people as well, but, there

always were and still are lots of adjustments to be made. Even though I saw a lot of my family and friends, and went home for weekends and holidays, Sharon was one of the *positive* people in my life. She knows I'm a fussy eater and she also knows what I really like. If she has leftovers from dinner and she knows I would like them, she brings them along.

Another very positive minded person is Kathy Pahl. Kathy is a Recreation and Activation Staff member. When there's a problem getting to some place special, she always manages to come up with a solution. If our needs can't be met one way, she keeps on trying until a solution is found.

Just by their examples of positive thinking, my Mom is changing the way she reacts to some of my requests. When there is some place I would really like to go or something I really want to do, she used to think about all the things that would make it difficult. Now she is starting to go at it in a different way. She says there is a big difference between "*positive*" and "*impossible*", and unfortunately, there are still lots of "*impossibles*". Now however, we can look for compromises together and neither one of us feels so badly about it. Our thanks to Kathy and Sharon for showing us the way. They are two very special people.

Here is the poem I wrote for Sharon:

You are the One

You are the one
Who knows what I go through.
The pain I have,
Physically and mentally.

You are the one
Who listens and talks
About my problems and my joys.
I can share everything with you.

You are the one
Who I can count on
To make me feel better,
Even when you're not there.

Everybody needs a close friend.
I'm lucky to have found mine.
I want to thank God
That you are the one.

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Getting Kids Communicating at School

DORIS MACINTIRE &
TRACY SHEPHERD



Tracy Shepherd

As clinicians working with children, the caregivers that we find ourselves most often working with are the educational assistants (E.A.) at school. These are the people that make a tremendous difference in the success or failure of an augmentative communication system. As with anything there are good and there are bad. One of the biggest obstacles is the transition between EA's. They change so often! Many times the child will get a new E.A. every year or even twice within one school year. A tremendous amount of time and training goes into helping these individuals learn to effectively program these devices and facilitate language learning and communication. It becomes very disruptive for the child to have to start from scratch building a relationship with new a E.A. as well as waiting until this new facilitator gets up to speed on their

particular system. I mention this not because I have a solution. I am not about to question or try to influence decisions made in the education system. I only discuss this issue so that others facing this problem might realize we are all facing the same dilemma.

*I felt that rather than talking as a clinician about caregiving I would go to the horse's mouth. I recruited an Educational Assistant to share some of her joys and frustrations with the **Communicating Together** audience. Doris MacIntire is an exceptional facilitator and has a heart of gold. She is working with a child who has cerebral palsy and lots of experience and energy which she brings to the job. I have had the pleasure of working with her over the last year and know she has so much to offer any child with whom she might work. Here are Doris's thoughts. We have chosen the pseudonym, Sarah, for Doris' student.*

From Doris MacIntire

As an Educational Assistant, I work with a 9-year-old girl with cerebral palsy whom I will call Sarah. During the past three years, I have worked with Sarah, we have created a very special bond. She was nonverbal at the time that I started, vocalising only a few words but not enough to express her needs and desires. I myself had a brother born in the 50's with the same condition as Sarah. He was institutionalised for half of his 12 short years without the oppor-

tunities that are available today. This led me to set a personal goal for this little girl. "Communication!"

Imagine what it is like for a person with a communication disorder. Imagine the frustrations of wanting to express your basic needs or simply wishing you were part of a conversation with friends but not being able to. Imagine not being able to decide what you wanted for yourself but instead having it decided for you! During my first year, we used the loop tape for choices and integration activities in the classroom. Sarah also used a Big Mac switch that enabled more spontaneity in communicating during circle time, class discussions, etc.

I began to introduce a modified and individualised sign vocabulary to express high utility words. Over time she began making progress with choices and scanning options. Sarah started using Ke:nx software to make those choices and answer questions to simple stories with the use of two Jellybean switches. Then with practice, encouragement, maturity and time, she has progressed to using bilateral head switches mounted on the wheelchair making it possible to scan options with one switch and choose with the other. This was introduced to her simultaneously with her AAC device she uses for communication, integration and entertainment.

The AAC device was received positively by myself, the family and Sarah herself. She loved the challenge of learning this new device and its advantages. When using a social interaction board

with a choice of personal news items in the school with friends and teachers, it was very rewarding for me (and I'm sure for her as well) to see communication happening without me prompting or interpreting. The options of using this device are unlimited. This device allows the child to be independent. When turned on, it automatically opens to a main menu where she can choose from scanning groups consisting of social greetings, personal information and a group that seems to be the most popular with her, a row I entitled "Fun Stuff". In this group there is vocabulary for games, choices for certain activities and vocabulary for certain situations (i.e. recess). There is also reading books, both for pleasure and oral and sight vocabulary. These books originate from a main library page where a choice automatically opens for the story to be read. She has to turn the page herself. At the end of the book there is the option of returning to the library or back to the main menu. It has been very beneficial for her to read stories to family members as well as to her friends and during "Reading Buddies" at school. Now she is able to be an active participant instead of a passive one.

The AAC device has been used in many situations. With it she has been able to take an important role in school activities. She has announced choir songs, participated in class assembly presentations and church functions and loves being able to order her own food in a restaurant.

As we are both still learning and discovering new ways to use the device, I feel confident that we have only just begun.

I don't want to leave readers with the impression that I have not had my share of frustrations with the AAC device. Sometimes, I feel as if I am working on commission sales for the company that sells the software. That is I have to prove and show staff members how it works to convince them that this child is entitled to communicate! Why is it when a child uses a device to read a story, some think it is "not really reading"? Do they not realise (or care) that the child would far rather read orally? Why can't people, especially in the field of education, realise a laptop computer can be used for other purposes (i.e. communication) than just storing data and producing work?

A device with all the capabilities as this should be accessible to the person constantly just as one would use his/her voice. My vision is that this will become a reality for the child with whom I work. Therapists involved with this device have tried to convince the school administration of the importance of having someone other than myself trained on the device so that in my absence it does not have to stay in the case. Due to the ever increasing demands on teaching staff and the length of time it takes to learn and program the device, this has not happened. As much as I enjoy taking an active role in the programming, I certainly would be eager to share this responsibility. Most people are very impressed by the device, how it is programmed and the length of time it takes. Unfortunately, I have had incidents where school authorities are not willing to

recognise the need for paid programming time. They fail to realise that a person can use an AAC device but it takes time to program. Sometimes plenty of time! If this is going to be successful, educators and family need to work together to share ideas and learn best how to satisfy the needs of the user.

I have felt a great apprehension with the responsibility of costly equipment in my care each day, especially when working in a school setting where accidents are inevitable. Another unavoidable and frustrating complication is technological problems. This is a machine! Things will go wrong! Being a very un-mechanical person, I have amazed myself at what can be learned when messing up! I have found no rhyme or reason behind some of the glitches I have encountered. Some days everything works like clockwork and the next you are positive everything is set up the correct way and there may be visuals but no sound. When having frustrations, I try to remember that I am fortunate that I can voice them, unlike the child patiently waiting for me to resolve the problem. When these situations occur, (always with an audience) I feel most people are justifying excuses for not taking a more active role in programming.

*Thank you Doris for your input and the great amount of time and effort you take to help the children you work with communicate. After all, that is what **Communicating Together** is all about.*

§

The Characteristics of Good Caregivers

NOLA MILLIN

Unfortunately, Reflections is going to be a short section this issue. I thought I would receive a lot of feedback about what makes a caregiver good, bad, or indifferent but I didn't get very many responses. So, I'm going to do a quick evaluation of some of the qualities I look for in a caregiver.

Dependability & Flexibility

Obviously, dependability and flexibility are essential traits for a caregiver. I need a caregiver to show up when I need them but, since I'm an active person, my schedule changes so the person has to be flexible. I may need the caregiver to go places with me as well.

Ability to Listen to Direction.

I'm a very independent person and I know their reasons for leaving have been mostly due to a change in their personal lives, which affected their job. A few left because they were terrible. When caregivers listen to me most people find my care isn't difficult. Also, I know how to set up my computer equipment and AAC Device but the attendant has to listen to my direction.

Great sense of humour

You might wonder what that has to do with caregiving. Well, if you know me at all you would know I tend to get myself into

some unusual predicaments. When a caregiver has a sense of humour, I feel like they care about me and about the absurdity of some of the situations we might get into together. I've named one of the attendants in my apartment building, "Miss Personality," because she has as much personality as a tree! Actually, a tree might have more! Although I receive the basic care from her, I find it difficult to relate to her. She doesn't show any *care* or *compassion* in the work she does.

"If the caregiver understands the purpose and how valuable it is for their client to have as much independence as possible, all will be happy."

Here are two examples of why having a sense of humour has come in handy with me.

First, most "accessible bathrooms" aren't made for a wheelchair user and a helper. Tracy Shepherd, who is a good friend of mine, is only one of the many people who have been stuck in an accessible bathroom with me! Tracy is at the point where she doesn't judge a restaurant by the quality of its food or service. Instead she runs in to see if we'll be able to get into and *out of* the bathroom without major difficulties. My friends (and caregivers) and I have learned to laugh at the idiotic way accessible bathrooms are made. I have had many people have to step over the toilet because they had cornered themselves in trying to help me.

The second experience involves another friend who on many occasions has been my caregiver. Colleen has this ability to lose me in elevators! She pushes me into the elevator then steps back out to grab something outside the elevator and the doors have closed with me inside the elevator without Colleen. Fortunately, I'm able to move myself so I've been able to get off at the desired floor and just wait for her. The funny part is that it has happened on more than one occasion. It has become a joke and I tell people if they don't see me for a couple of hours I'm probably riding an elevator!

I realize that other traits might be more important to other people but these are the qualities that I feel make an excellent caregiver for me.

Now, here's a parent's point of view:

Kathy writes:

I am a parent of a disabled adult daughter. We have seen several caregivers come and go, caregivers we could not trust. One we could not trust with Gina's safety and the other stole money from her.

For the most part, we have been blessed with very good providers. My main concern was that the

caregiver had respect for Gina and our family. If there is no respect, they will fall short in responsibilities for safety and fulfilling personal care needs. We conducted long interviews to get a feel for the provider's personality and experience before hiring. After showing the caregiver the tasks necessary for Gina's well being, we made sure the provider was able to accomplish them.

Since Gina lives at home, it was very important to hire someone who would fit in with the flow of

the household. It was great to have someone we could joke with and who took some initiative to find things of interest to entertain our daughter. This really took the pressure off me to come up with things Gina and the provider could do while the laundry was being done and during the times I had to leave the house. There is more to life than watching T.V.!

It is very important for them to understand the purpose and use of Gina's AAC device. They are not

there to program it (Gina does that on her own) but to have enough knowledge to allow Gina access to it and set it up for her. They also have to know how to get her up to her computer, turn it on and put in programs for her. The provider must be aware of the purpose and use of all the client's adaptive equipment and how to set it up for the client. If the caregiver understands the purpose and how valuable it is for their client to have as much independence as possible, all will be happy.

§

AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

*The Official Journal of the
International Society for Augmentative and Alternative Communication*

**Editor: Pat Mirenda, Faculty of Education. University of British Columbia,
2125 Main Mall, Vancouver, BC V6T 1Z4 Canada,
602-822-6296 (phone) 604-822-3302 (fax) E-mail: pat.mirenda@ubc.ca**

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Caregiving for Profit

GEORGE PIGACHE



George Pigache

profit motive does not necessarily mean responsive or responsible caring. So in this issue, I plan to look at the plight of caregivers paid by agencies and the plight of the people they are supporting.

This world is becoming increasingly privatized and individual greed is spreading over society's responsibility for its members. More and more, tasks which used to be preformed by the public sector for the public wellbeing are now being provided by private agencies for profit. When caregiver becomes 'privatized' with for-profit agencies, there is undeniable pressure upon businesses to make a profit, not just to provide services. They also have to attract shareholders, and pay advertisers and other interested parties supporting them. The direct effect of this for the caretakers they employ is that they often receive lower wages than caregivers working for public agencies. Thus they do not have a strong commitment to stay should a higher paying position arise.

The need for a profit also means that in the private sector, however good and caring a caregiver may be, they are very often are not allowed to devote the time they might wish to any one client. This has already begun to show in reduced services especially in the little peripheral kindnesses which caretakers were often able to provide. Now, with

caretakers moving from client to client, providing very specific tasks in specified periods of time, they have lost the flexibility which often made their work so rewarding.

These problems become further exacerbated where the client relies on augmentative communication equipment to communicate his or her needs. Whether the communication equipment involves high-tech software and hardware or is a low-tech device such as a word board, caregivers need to be fully trained in its usage. The fact that agencies in the private sector have to show a profit often prevents them from providing time for a staff member to receive the training needed to feel comfortable using the equipment prescribed for their client. The common practice is for the user's family and other significant people to be trained in the appropriate use of the individual's communication equipment. Before the introduction of *exact billing* and *prescribed time frames*, it was possible for a caregiver to also learn how to use equipment. Now when service schedules are arranged to make profits, training, which could be considered not to be profit making time, may not be factored into tenders submitted to provide service. The result is often caregivers do not know how to communicate with the clients they are working with.

Caregiving is an honourable task, possibly one of the most honourable of tasks. Whether it is performed by a family member, a close friend, or by a person employed to do it, such care, understanding and empathy can be incredibly demanding. Add the need to support someone who uses augmentative communication to meet their needs and wishes, and the responsibility becomes even harder. Family or friends with help, will do their best to learn the communication needs of the people they are looking after. However, responding to a

In Ontario, the provision of care in the community is becoming increasingly privatised. Agencies submit tenders for three year contracts. This means that every three years when contracts are put up for tender a new agency may take over the care. If this happens the clients, in all likelihood, will all get different caregivers. As well as the obvious loss of someone who has become at best a close friend, or at least an efficient person knowledgeable of their needs, the client now has to face the prospect of retraining the new support worker in how to communicate with them. If we are going to go

down the path of agencies submitting competing tenders, it is going to be important that when requests for proposals for service are made, the requests include descriptions of specific needs in the area of communication. Then agencies submitting tenders can include the cost of training staff for this area. This cost should also be shown in their proposals.

Levels and forms of care are going to change. Whether or not the changes will be for the better, are yet to be seen. A lot of the rules have not yet been written. This is the time to address the issue of care for augmentative

communication users. Teaching people to use communication equipment has always been a problem. If there is one advantage in the change over to new approaches, it is that this is the time when communication users have the chance to write the rules on how caregiving will be provided in the future.

§

Some Future Associate Editors?



Tracy, her new twins, Sean & Brendan Nicell, and her husband, Mike.

Re ComTog OnLine

Our new address for our **ComTog OnLine** website is:

<http://www.comtog.net>.

We had to change our address because we needed to change our Internet Service Provider. We apologize for the disruption of access while arrangements were being made. For those who wish to browse and explore a sample of the online issue, we invite you to check us out at our new website.

As You Help Us

PAUL MARSHALL

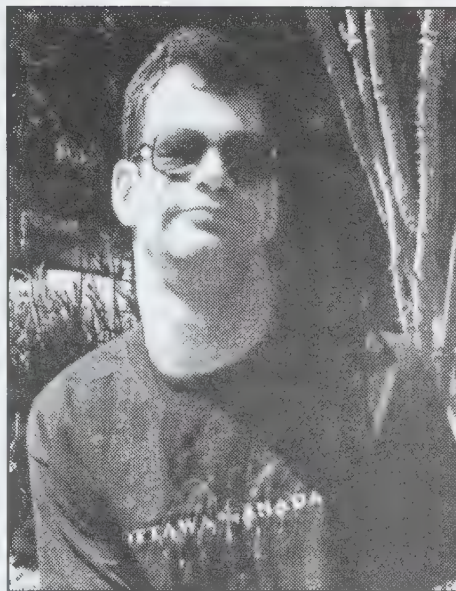
As you help us,
Just remember within this body
of silence,

There is a Real Person.
With feelings, dreams, wishes
and hopes.
Treat us as you would others
Treat us with the respect that we
so badly need from you.

We aren't asking for the moon.
We understand that everyone has
their weaknesses.
But just understand that we
have them also!
We aren't asking you to be
perfect in all that you do for us.
We are asking you to be our
voices, hands, and our feet
Because ours just don't work
the way they should.

Be full of compassion when
you reach out to help us,
And in turn we will be full of
compassion to you.
If you give a smile,
we will offer it back.
We understand there are
rainy days, but please
accept ours also.

Let's be friends,
Let's not dwell with each of
our bad points because
nothing is benefited or gained
from them.
Instead! Let's dwell on the
positives, they are many!



Paul Marshall

Let's have a party because
the day is too short for negatives
We will try to see you as a person,
as you do things for us.
Let's share our concerns so
we can know our hearts.

As you help us,
We are full of thankfulness
within our silent bodies.

Thank you for your voices,
hands and feet!

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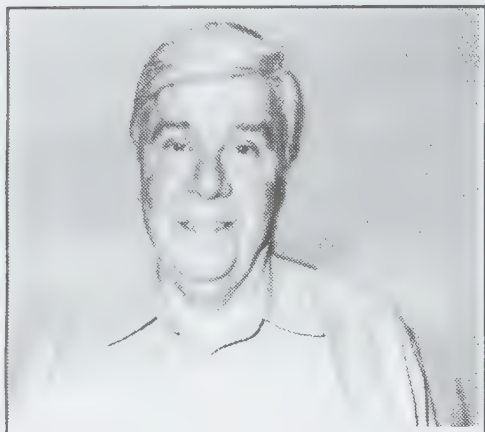
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Chatting on the Internet

PETER LINDSAY



Peter Lindsay

*In the last issue of **Communicating Together**, I talked about three basic functions of the Internet that are important for the AAC user. The first is its library function. The Internet is the largest accessible repository of information in the world. The second is its storage and distribution function. The Internet is rapidly becoming the major worldwide resource for storing and distributing information of all types from the latest hit CDs to books to computer programs. The third is that the Internet offers exciting new communications opportunities. In the last issue, I discussed the most popular of these new communication vehicles — e-mail. In this issue, I will explore the second most popular program for interpersonal communication on the internet - the Chat programs. Helping AAC users to be able to use these chat programs will have implications for their caregivers. We will save a discussion of those implications however until after we have looked at what chatting is all about.*

As was noted in the last issue, one of the advantages of most e-mail programs for the AAC user is that the messages can be prepared "off-line". This gets around one of the primary impediments in face-to-face communication, namely that the effectiveness of the communication depends on the speed of the communicator. With e-mail, speed is *not* an issue.

A second advantage of e-mail for AAC users is that the messages can be prepared, addressed and sent by the individual with physical disabilities completely independently without requiring the intervention or assistance of the individual's caregiver or anyone else. The third advantage is that once the message has been composed and sent, the actual transmission is much faster and more efficient than regular mail.

The above factors relate to a feature that all e-mail programs have in common. They all involve *asynchronous* communication. This means that the message sender and receiver do *not* have to both be connected to the computer at the same time in order for the message to be communicated. *Synchronous* communication on the other hand does require that the participants in the communication exchange be connected to the computer at the same time. Communication programs that involve synchronous communication go under the general heading of *Chat* programs.

Text telephones

If e-mail is roughly equivalent to sending regular mail, chatting is equivalent to telephoning. The

primary difference is that you use text rather than speech to encode your message. Unlike e-mail, chat programs allow you to send messages instantaneously to someone *who is on-line at the same time as you are*. The person you send the message to receives it on his or her screen instantly as soon as you send it. Because you both have to be on the computer at the same time, this mode of communication is called *synchronous* communication. Unlike e-mail but like face-to-face communication, chatting is dependent on the speed at which the user is able to compose and read messages. Also unlike e-mail, reading and composing messages must be done on-line while you are connected to the computer.

Chatting on the internet is becoming almost as popular and appealing as e-mail. As with e-mail, you can communicate with just one person or with a whole group of people at the same time. Chatting in groups is usually done in "*chat rooms*", a form of communication that is becoming amazingly popular. In a chat room, a number of people enter the room electronically to engage in a discussion with each other on a topic of common interest. Just as in real life, proper "*netiquette*" expects that you will introduce yourself when you join a discussion already in progress. In fact, in most chat programs, you really can't sneak into a room and eavesdrop without anyone noticing. Chat programs are usually set up so that the others who are already in the room will see that you have entered even if you haven't said anything yet.

Interacting around topics of common interest with people who may be half way around the world and who may start out as perfect strangers is surprisingly addictive for many people. Because of this, thousands of chat rooms have been set up for people to talk to each other on almost any topic in any language at any time of the night or day. For those nights when you can't sleep or just want to while away some time, you can always find someone to chat with about something. The more advanced chat programs now allow you to exchange video and audio information as well as text.

Chatting however has risks. The basic problem is that you really can't be sure that the people you are chatting with are really who they say they are. Even though people may introduce themselves in one-to-one chatting or when they enter a chat room, they almost always use a pseudonym and sometimes adopt completely fabricated personas. Thus in a chat room, you really don't know for sure whether the people you are chatting with are young or old, male or female, dangerous or benign. You only know what they say. Part of this may be harmless, done just for the fun of playing a completely different role. Sometimes however, the role playing may be for malicious or even dangerous purposes.

Just as for e-mail, the anonymity of chatting can of course work to the advantage of someone with disabilities. Many times, people with disabilities do not want their disability to dominate an interpersonal situation. They wish that they did not have to disclose their disability to the rest of the group until they have had a chance to get to know them. Chat rooms

allow you that luxury. It can also lead to dangerous situations however particularly for young AAC users who may be naive in the ways of the world. They may actually believe everything someone says in a chat room.

For some types of communication, chatting is very much more appropriate and efficient than e-mail. When there is a need for an immediate response and several exchanges of information, chatting is to be preferred over e-mail. It is very much better for example if you are trying to decide on a time and place to meet for lunch or are setting up a meeting among a number of people. It is also good, however, for long leisurely discussions when you are just getting to know someone such as those that might be had on the phone late at night.

These are some of the general issues relating to chatting and chat rooms. Let us look now more specifically at what the various chat programs do and what you need to get involved.

Common features of chat programs

Functionally, all chat programs have essentially the same basic features. To chat with someone, the most important constraints are that both of you have to be connected to your computers at the same time and have the same chat program running. Furthermore, you both have to know when you are on-line at the same time. Thus, the chat program must have a way of keeping track of when you and your friends are signed onto your computers. In order to do this, you indicate to the program the people with whom you might like to chat and how to reach them. Most programs accomplish this by allowing you to set up a "buddy

list" containing the e-mail addresses of people with whom you would like to chat. Once set up and activated, the chat program will keep a lookout for your buddies. As soon as the chat program tells you that they are on-line, you can start a conversation by simply clicking on the name(s) of the person(people) with whom you want to chat. The chat program will make the connection automatically. Chat programs of course will also allow you to put up a "Do not disturb" sign to indicate the times that you don't want to chat or that you are available only to certain people on your buddy list.

Chat programs allow you to communicate one-on-one with friends and family. They also allow you to communicate with groups of complete strangers. One of the most important and novel features that internet chatting brings to our culture is an easy and motivating way for complete strangers to communicate with one another. Once you have a chat program, it is extremely easy to find chat rooms and people to chat with on almost any topic you are interested in discussing (see below). In fact, one of the curious features of the newer chat programs that is amazingly popular is a feature that allows you to ask the chat program to choose someone completely at random who is currently on-line to initiate a chat with. Some people seem to be totally entranced by this activity. They start up their chat programs as soon as they sign onto their computer in the morning and leave them on all day hoping that someone will call them to chat.

Some popular chat programs

ICQ (*for "I seek you"*) is one of the first chat program that came

into wide use. This program is very easy to use and became very popular in part no doubt because it is totally free. It is still widely used and available free for downloading from the internet site:

<<http://www.icq.com>>

Netmeeting is a program that provides a full range of interpersonal communication functions in addition to chatting. In *Netmeeting* you are able to exchange text messages instantaneously (i.e. you can chat). In addition, you are also able to exchange speech messages and hence to conduct free long distance conference calls (provided your computer has a microphone and speakers), or live video transmission and reception and hence to conduct free video conferencing (provided you have a small video camera - a "webcam"), or exchange pictures or computer programs and files. In short, *Netmeeting* is a general purpose program for interpersonal communication and information exchange. It is available free from Microsoft on their Website:

(<<http://microsoft.com>>).

The very success of *Netmeeting* illustrates one of the major problems with chat lines. When you register with *Netmeeting* and activate the program, all other *Netmeeting* registrants can see that you have signed on. Since *Netmeeting* is distributed worldwide, literally thousands of people from all over the world will be informed. It is like publishing a toll-free phone number in a worldwide telephone directory and telling everyone that you are home. Anyone can call you free with the click of a mouse. The result is that you can get deluged with calls from all kinds of people you don't know and, in most

cases, don't want to know. Often the caller on the other end is offering services that may be legal on the internet but are not legal in most countries. There are ways around this problem but the deluge can be shocking when you first encounter it.

Chatting and the AAC user

At first glance, it might seem that for someone using AAC, chatting would not be nearly so useful a communications tool as e-mail. After all, it has the immediacy of speech and hence puts speed back into the communication equation as a determining factor. While this may be true, it is really too soon to dismiss the possibility of AAC users using this new internet communication tool. For one thing, some of our more literate AAC users who have tried chatting seem to enjoy the experience immensely. They find it an extremely valuable addition to their communication opportunities.

Another group of AAC users who may not be as literate as the first group are in the process of learning to read and write. Chat lines for this group could also be a useful tool. They could, for example, be used to exchange messages between two "e-pals" as part of a literacy program for nonspeaking individuals. In this case, neither participant would be particularly concerned about speed.

Still another group of individuals, the caregivers, could find it useful for interacting directly with a clinic or doctor or for discussing some of the problems they face among themselves. Again, in this case, the speed of information exchange presumably is not the crucial factor.

Eventually chat programs may even be used as a text substitute for the way speaking teenagers use

the telephone to talk to each other. Most speaking teenagers seem to like to talk endlessly on the telephone about what appears to the rest of us to be nothing. Someday, chat programs may very well provide the equivalent opportunity for our nonspeaking teenagers. All in all then, chatting is so new that it is impossible to predict its future. Thus, it is foolhardy at this point in time to try to limit its uses in the AAC community. Probably the safest thing to do now is to make chatting available to as many of our AAC users as possible. Let them show us its most valuable applications.

Chatting and literacy

As discussed above, even though chatting is sensitive to the speed of the communicators, this in itself should not prevent AAC users from taking advantage of this new communication tool. A second apparent barrier for the AAC user would be the apparent requirement of at least a minimal level of literacy. Both e-mail and chatting are done in print. In fact, most of the information on the internet is print based. This means that individuals with limited literacy skills — clearly the majority of our AAC users — are going to be at a disadvantage. The question however is whether this predominance of print actually *precludes* AAC users from using it.

Fortunately, when the issue of literacy is explored in depth, the picture is not so bleak as it might at first appear. For one thing, there are a number of AAC users who are completely literate. The predominance of print on the internet does not pose an access barrier for them. In fact, for these people internet programs like e-mail and chat provide fascinating and

highly motivating new communications tools for practising and improving their literacy skills.

Second, internet communication programs should be very useful tools even for individuals with more limited literacy skills. Unlike the first group however, these individuals will need assistance to use these tools. A task that may be done completely independently by the first group may well require some support for the second group. The fact that they need assistance however, does not mean that the second group should not be allowed to benefit from the experience. It just means that to use e-mail, to chat and to surf the net, the second group will need support from someone — most likely, their aides or caregivers or perhaps their families.

Expecting caregivers to help their charges with chatting and e-mail however does impose some additional new expectations for the kinds of technological training caregivers will need in the future. Technical training of this sort is usually not contained in their current job descriptions. These new requirements of course would have to be spelled out and negotiated in advance. They should not however end up however as being the main barrier that prevents this group of AAC users from benefiting from what the internet has to offer.

A third contributing factor is the rapid development of computer-based programs that can read text files to an individual. At the moment, the primary motivation for developing these *text-to-speech* programs is to make the internet accessible to the blind. Although these programs are designed primarily for persons who can't see the print, in principle they are just

as useful for the person who can't read the print because of limited literacy skills.

Text-to-speech programs then could be used by AAC users to read e-mail or chat messages if they are unable to read them for themselves. In addition to reading text files, *screen reading* programs are now available that will read what is on the person's computer screen. These programs are specifically designed to help a person who can't see the screen navigate through the highly complex inter-related connections associated with typical internet sites. Like text to speech programs, screen readers are just as useful for those who are illiterate as they are for those who cannot see.

Fourth, some relatively new legislation is promising to accelerate the development of tools to make the internet even more accessible for people with all kinds of disabilities. The most prominent example of this is *The Americans with Disabilities Act*. This act now guarantees equal access of all Americans with disabilities to everything from airlines and hotel rooms to computer terminals. This is going to dramatically influence everything including the design of the internet interface screens themselves. It is now a legal requirement that they become more user friendly and less dependent on the user being able to access the printed word.

Fifth and finally, the AAC user's access to the internet will be further supported by the recent development of specialized programs specifically designed for processing, on the internet, the graphic symbols that AAC users use on their interpersonal communication systems. One example of such a program for a specific AAC

symbol system is *BlissInternet*.

This program is designed to permit AAC users to compose and exchange e-mail directly in their own AAC language, Bliss, with anyone else who is using Bliss. It also has a translation component for those who want to interact with Bliss users but who do not know Bliss. Presumably the distributors of other symbol systems will follow suit when there is sufficient pressure from their clients for them to do so.

In summary then, even a lack of literacy is not an absolute barrier to being able to use the exciting new interpersonal communication tools offered by the internet. Only our lack of determination to make these tools available to the AAC user will pose an insurmountable barrier. To support AAC users in accessing these communication tools, however, it seems that caregivers and aides are the most logical candidates to play a central supportive role. The question then becomes will they be willing to do so? Is it reasonable to expect them learn how to use e-mail and chat programs so that they can help their charges use them? I asked Kari Harrington, an inveterate chatter and frequent contributor to **Communicating Together** for her comments on these questions. As you will see below, Kari raises an interesting question: Just how will the increased unionization of care-givers affect the possibility of modifying their the job descriptions to bring them more in line with the modern computer and internet era.

From Kari Harrington

Where I live, you could be pretty sure that a resident's parents would want to assist in helping their charges get on the internet,

especially if they live close enough for them to come on a regular basis. I know we have volunteers who help in the school here and come to do other things with the residents. I don't think however, that there are many other residents who have computers of their own as yet. They get to use them in the school room on a regular basis. Some of the Life Skill Staff help the residents to send and receive e-mail letters.

The Attendant Care Staff have a union now and have an agreement on what their job is and what they must do each shift. They seem to do just what the job requires them to do and no more. I don't know if any of them have any experience with computers or if they would even be interested in helping. I don't think so, but I don't really know.

The exception is Sharon Smith whom I wrote about in the *Perspectives* article in this issue. She and I often have a good computer to computer session on a chat line. It's great and I learn a lot too. Sharon was the one who got me chatting and she always encourages me to try new things on the computer.

So how do I get started?

Assuming that I have persuaded you that it would at least be interesting to try chatting, the question becomes what do you need to get started. Basically, you need two things to chat — a chat program and a place to find different chat rooms. For the chat program, I would recommend starting with the ICQ program discussed above. As was noted before, this is probably the most popular program. It is free, and it is very easy

to use. If you want to find it on your own, you can do a search for the terms "ICQ" plus "download" to find locate possible download sites on the internet. You will find many of them. Probably the best and easiest place to start however is:

[<http://www.icq.com/download>](http://www.icq.com/download).

This same site also provides a complete manual on how to use ICQ. Once you have downloaded and installed ICQ, you can follow the directions and set up a buddy list.

If you want to explore different chat rooms, there are a number of places where you can find interesting groups to join. The following sites have been suggested by Pam Proctor, a friend of mine who is a dedicated chatter. Pam has survived a number of life-threatening health problems. She discovered chatlines were very useful to her in coping with long periods of convalescence and depression. According to Pam, the best place to start when looking for interesting chat rooms is:

[<http://about.com>](http://about.com).

"This is my favourite site for chat rooms and for interesting information on a million different topics, a very user friendly site. *About.com* has rooms that address hobbies, health issues, religions cooking, anything."

Pam also recommends:

[<http://chat.tripod.com/>](http://chat.tripod.com/)

particularly the "*Connection*" chat room for men and women with disabilities.

While Pam loves chatting and hopes you will too, she also has a warning that she learned through bitter experience "*Do not share any of your personal identifying information on a chat line. Apart from that, tell them to ENJOY themselves!*"

A closing anecdote

Let me close by sharing an anecdote relating to one AAC user's use of chatting. One of the most interesting uses of chat lines by someone who does not speak was mentioned in our previous issue on *Sexuality* (March 1998). The author of the feature article in that issue, Anne Abbott, noted that she was an early experimenter with chat lines. She used to sign on pretty regularly to an afternoon chat line used by a rather varied group of young people her age. As far as she knew, none of them were physically disabled. This group used the chat line regularly as a sort of electronic cocktail hour to discuss the day's activities and to make plans for various outings. Anne was able to keep up with the conversations using a combination of the abbreviation-expansion capability of her communication program and previously prepared messages. No one had any idea that Anne was profoundly physically disabled and could not speak.

Finally, one of the participants, intrigued by Anne's poetry and corny jokes and the fact that she never seemed to go out with the group, decided he wanted to meet her and take her out to dinner. With considerable trepidation and preparation on Anne's part, they finally did meet face to face. Fortunately they knew each other well before they met. They were married one year later.

§

Learning to Read

SHIRLEY McNAUGHTON



Shirley McNaughton

*I have just returned from a Bliss meeting in Capetown, South Africa, where among many other exciting activities — meeting old and new AAC friends, working on new symbols with other International Panel members, visiting Capetown programs for persons with disabilities, savouring the beauty of South Africa — I had the opportunity to give a lecture on “language” to an audience of AAC professionals, parents, Bliss colleagues, and students. Because I would be out of the country during the preparations for the Fall issue of **Communicating Together**, I was given a holiday! Little did I know that a SymbolTalk was in the making during my absence, as Paul Marshall prepared a presentation on literacy for the September “Aug Com Rounds” in Toronto. I am very pleased to welcome Paul to SymbolTalk. In the next issue, I look forward to discussing some of Paul’s observations regarding his literacy development and sharing some of the thoughts on language and literacy that I presented in Capetown.*

From Paul Marshall

When we talk about literacy in AAC, quite often the playing field gets totally turned up-side-down. How do we teach these people to read when they can’t say sounds or words out loud?

I want to go back into another world and another time for a bit. We are going back to the early 70’s when there weren’t computers, speech output systems or any other high-tech equipment. There were just electric typewriters. Now this seems the dark ages for me. I was about ten years old, and had an extremely excellent family and a farm environment to develop my wings so I could learn how to be a survivor. The one thing that was holding me back was that I had no way to communicate with my world. Because of this, my English skills fell behind greatly. I could pick words out if a person said them and asked me to pick the word out. But when it came to reading, forget it! I can remember my weekly spelling tests. All that I did was memorize how the letters came in each word! I wasn’t sounding the words out. By 12-years-old, I was starting to get very depressed and didn’t want to do anything!

My breakthrough was when I learned Blissymbolics. In that first year, I changed from a depressed boy into a boy who was able to communicate well for the first time in my life and was ready to take on things. I fully believe that I needed to be able to communicate with my world before the learning

process of literacy could even start! Not a doubt in my mind, Blissymbolics was the cornerstone that really catapulted me into the world of literacy. I would be putting up a front, if I said I don’t still struggle with reading. However, over the years, I have been able to develop numerous skills to cope with my reading and writing limitations.

First, I am going to get myself into some hot water and try to do some swimming against the flow of a mindset that seems to be crawling into the culture today. That mindset is that high-tech equipment is the answer to everything. I will say that I don’t believe in giving any high-tech equipment before children are ready. Don’t get me wrong, I believe that high tech equipment is the greatest bridge that narrows the gap between the nonspeaking community and the mainstream of our society. I guess it is partly my farm upbringing, however, that prevents me from seeing anything wrong with letting some struggles come into the life of a child who is nonspeaking. I can already hear the, “But Paul, shouldn’t we use everything that will allow our?”

In many cases, a system like Blissymbolics that requires only a low-tech symbol board, offers the literacy framework that acts as a foundation from which other learning can take place. To me, it is critical to have this foundation, before any high-tech device is introduced. A system like

Blissymbolics gives sentence structure, plurals and proper endings and many other grammar rules. As you can see, I swing to Bliss partly because it was my own springboard giving me the foundation that I needed to slowly integrate fully into the printed word. But Bliss teaches a whole host of language capabilities that flow easily into the world of print. I am sure that we all would agree that our goal is to get our children to the point where they are fully integrated into the world of text as soon as possible. Whether the method is high or low technology, it doesn't matter as long as the transferring from one system to words is done correctly. We must be willing to provide all of the alternatives to suit the learning style on an individual basis. I would like to reference an article that Shirley McNaughton wrote called "*Climbing the Literacy Ladder*". It is on the Blissymbolics Communication International website:

<http://home.istar.ca/~bci/literacy1.htm>.

My own journey through the process of integrating fully into the printed word will be a lifelong trip. I am always improving my literacy skills. But let me tell you what I use when I am writing. I use a word processor with a spell checker, a word prediction program, and a voice output application that reads each word and sentence that I type in. Plus, my dictionary and thesaurus are always at my finger tips. I use them both to look up alternative words. I am often in a book, learning new words. When I write an article or presentation, I still

greatly appreciate getting it proof-read by someone else. Now that you know all of my secrets, you can tell the world "that Paul guy is a fake!"

I do a great deal of work at home and communicate with people by e-mail. I can remember when I started interacting with people via e-mail, I was scared to death to send out messages because I wasn't comfortable with my literacy level. Now that I have hundreds of "sent messages", I feel quite at home with sending messages to anyone. Sure, I make a few mistakes, but I think it is quite common to see a few spelling mistakes, especially in e-mail messages.

There is one small story that I would like to tell you. Just last week, a man wrote me from San Jose about a website that I maintain. He didn't know that I was nonspeaking. Probably he thought he was sending a message to another professional who maintains a site. That one day, I think we interacted about three different times. We had a wonderful chat. Who knows, maybe he also had a physical limitation himself! As we all know, communicating via e-mail takes away the physical barricades and you interact totally by the printed text. Quite likely, I use the printed text for communication much more than many people. After all, every time I communicate, I am spelling. What greater way is there to master literacy skills!

You can see why I deeply believe in enabling our young AAC people with the gift of literacy! I learned Bliss at twelve, which started me on my literacy

journey. It wasn't until I was in my mid-twenties before reading and spelling began to really click! Quite likely if I had been much younger when I learned Bliss, my literacy skills would have come quicker and better. You could say that I had about twelve years of so-called dry ground before I or anyone saw any literacy fruit. So if a kid doesn't pick up the skills overnight, just know that the process might take them longer to master than it does for speaking kids. It is wonderful if our AAC young people can pick up the skills of reading normally and in the normal way. But if they can't, I think we need to try to give them a foundation of seeing words and hopefully teaching or guiding them to be ongoing travelers on the road called literacy. Teach them to listen to people, to understand how words and sentences are strung together. Teach them to watch or listen to the news and then scan the newspaper. You would be surprised at how much is picked up! No doubt what improved my literacy was sending and receiving e-mail messages, and writing articles and presentations. Plus, I am always writing and reading and I learned to be a student of books.

I hope my experience and thoughts will help you in some way! §

For more information about *Express Yourself of Minnesota*, or to purchase a copy of the video, please contact us at:

Express Yourself of Minnesota,
Inc.
PO. Box 19227
Minneapolis, MN 55419-OZ27
Phone (612) 866-8482
Fax (612) 866-9464
E-maileymtalk@aol.com
www.expressyourself.org

"Self Advocate: We Can, We Will, We Did!"

PEG JOHNSON

Express Yourself of Minnesota Inc. has sponsored and coordinated the YES (Your Expressive Society) support group since October, 1989. This support group provides ongoing training and encouragement to individuals learning to communicate better. The members have come a long way. When the group began, people left their devices at home or they brought them in needing to be charged or in need of repair. Ten years later, most of the participants are active in the community. The video described below shows the results of what such a support group can accomplish.

This is our motto. As one group member stated "The purpose of YES (*Your Expressive Society*) is to help members become more independent and involved citizens." YES provides ongoing support to participants to develop the communication skills necessary for self advocacy. In addition, more confident participation within the members' own communities (family, work, church or play) is encouraged.

Because we have worked so hard and are so proud of our accomplishments, our group decided to make a 30 minute video to share with others who might benefit from our experiences. We truly hope that a glimpse into the lives of our members might inspire and educate others who are struggling with communication issues in their own lives.

After meeting the YES members, the video introduces Rosemary. Using her communication device with the telephone, Rosemary arranges a ride

to the mall for a much needed shopping trip. Knowing that she can accomplish this trip independently, we follow Rosemary through the mall and stores as she advocates for herself; educates others (especially able-bodied shopkeepers!) and has a good time accomplishing her mission.

Throughout her life, every Sunday morning during worship Mary Louise has listened to others read the scripture lessons. The video captures a dream come true for Mary Louise as we see and listen to her read the scripture lessons with her communication device. The joy of this occasion is evident on Mary Louise's face as well as on the faces of the congregation.

Next, we meet Greg. We watch Greg and his determination tell about selling 1000 raffle tickets to earn a trip up to the beautiful boundary waters of Northern Minnesota. The camera reveals his great sense of accomplishment and pride.

Everyday decisions and interactions, which able-bodied persons may take for granted, are featured in a conversation between Connie and Peg. We listen as Connie uses her commu-

nication device to discuss upcoming activities with her friend. During their interaction, Connie's personal care attendant interrupts Connie with her own agenda. Connie, however, is able to assert herself and let her wishes be known and understood.

Following David at his work place, we see how his delightful and charismatic personality affects his co-worker and supervisor. David accomplishes his work with determination and his joy for life is openly expressed to everybody. Throughout his childhood, David shared through singing. Now, David uses his communication device and continues to inspire others through his music.

As you read the stories of these individuals, perhaps you will become more aware of how the loss of your voice and/or ability to communicate would affect your life. The mission of YES is to spread the word so that more and more people realize that *the ability and right to speak is a basic human need!*

For further information, see the bottom of page 22.

§

JOIN ISAAC NOW

The International Society for Augmentative and Alternative Communication (ISAAC) offers members reduced rates for:

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49 The Donway West, Suite 308,
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Communicating Together was established in 1982 and has been published quarterly since 1991 by *Sharing to Learn*. Beginning in 1997, it is available both in hard copy and as **ComTog-Online**. The magazine's mandate is to provide a means of sharing the life experiences and communication accomplishments and challenges of augmentative communicators. Its readership includes augmentative communicators, friends, assistants and supporters and all members of the community who wish to know more about those who use augmentative and alternative communication (AAC).

Co-editors:

Peter Lindsay & Shirley McNaughton

Associate Editors: Suzanne Clancy, Paul Marshall, Nola Millin, George Pigache, Tracy Shepherd, Alda Steprans, James Stuart.

Editorial aid: Barbara Reid

Administrative Assistance: Bob McNaughton

Subscriptions: Ruth Kennedy

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Communicating Together

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Phone enquiries: 519-766-1757

Fax: 519-763-6682

E-mail: plindsay@oise.utoronto.ca
smcn@freespace.net

Website: <http://www.comtog.net>